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ABSTRACT

The handbook provides an overview of developing and operating a respite care program for mentally and/or physically handicapped persons. The following procedures are addressed: staffing, setting fees, funding, recruiting service providers, training service providers, informing families, and referring requests for respite care. Sample forms, including registration cards, application forms for registry members, and medical release forms are appended. (CL)

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A COMMUNITY RESPITE CARE PROGRAM

FOR THE

MENTALLY RETARDED AND/OR PHYSICALLY HANDICAPPED

A Handbook

by

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To my daughter, Marla, whose birth opened up for me the world of mental retardation.

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INTRODUCTION

Raising "normal" children is, in itself, a difficult task for both parents and, in particular, the mother. Add to this the constant care of a mentally retarded and/or physically handicapped child or adult and what can result is a strained, tense family unit. Sometimes this pressure and frustration affects the other members of the family and may result in marital difficulties, sibling jealousy, overprotectiveness of the handicapped individual, or premature institutionalization. Conditions are further aggravated when other family crises exist, such as an illness, death in the family or financial stress.

Too frequently, the individuals most directly involved with families of handicapped children and adults are not aware of the concept of respite care as a necessary component in the continuum of services to the handicapped.

Respite care is defined as short-term or temporary relief care for families of mentally retarded and/or physically handicapped children and adults, either in or out of the home in order to allow the family to 1) meet emergency needs; 2) fulfill vacation plans; 3) obtain routine reprieve, and 4) provide an alternative to institutionalization of the handicapped individual.

In the past few years, there has been growing recognition and support for respite care services; however, too few programs exist on a "grass-roots" level to adequately satisfy this nationwide need for intervention and supplemental support services.

One community-based program that seeks to meet this need is the Childcare Assistance Program for Special Children, Inc. (CAPS), a private, non-profit referral service for respite care in the Northern Virginia area.

There are other models of respite care programs in the United States (which will be discussed later in this handbook); however, because the Childcare Assistance Program for Special Children (CAPS) is a cost effective program, has a high usage rate and is simple to administer, CAPS will be the model presented in depth. While reference will be made to the handicapped "child" throughout this handbook, all ages are implied, from the newborn to the elderly.

It is the intent of the author that this handbook will serve to motivate parents of handicapped individuals, educators, community leaders, agency coordinators, and concerned persons to develop a respite care program in their community.

RESPITE CARE: FULFILLING UNMET NEEDS

For those parents who need short-term relief from their handicapped child, respite care is a valuable and compassionate answer to the problem. A night out, a long overdue vacation without the handicapped child, coping with emergency situations, going shopping for the day -- these privileges are often denied parents who cannot find adequate and reliable care from babysitters, relatives or neighbors.

Trained persons providing respite care, both in their own home or in the home of the child, allow the family a measure of relief and security. The option of hourly, daily or weekly respite offers them flexibility in scheduling and meeting their own demands and needs.

While many public and private residential facilities offer temporary care, the removal of the handicapped individual from the family unit, even for a limited period of time, is frequently upsetting and disruptive to everyone concerned.

A respite care program not only serves the handicapped and their families, but also encourages direct community involvement by exposing the community to the handicapped, their families and the implications of raising such children. Providers of service rarely perform this service for financial reasons; rather, they want to participate in a meaningful activity. Thus, both provider of service and the family benefit from each other in a most humane and rewarding way.

CAPS' model as a respite care program is not presumed to be the best, nor the most adaptable to all community needs; however, due to the simplicity of its administrative procedures, its low budget cost and its utilization of community persons, it is viewed as a model which could be replicated in many locations with necessary modifications.

It is hoped that this handbook will serve to stimulate and encourage the need for respite care programs on a community-wide level, offer guidelines for implementation of a respite care program, and motivate interested persons to view respite care as a necessary and vital service which assists families in coping with their day-to-day responsibilities, as well as preventing unnecessary institutionalization.

ESTABLISHING A RESPITE CARE PROGRAM

One of the first steps toward establishing a program in your community might be the determination of need for respite care. This involves such information as the handicapped population; what other respite care programs exist, if any; whether parents prefer that care take place in the family home or in the home of the provider of service; how frequently respite care would be used and for what purposes; how much parents would be able and willing to pay for such care, etc. Much of this information could be gathered by use of a questionnaire distributed to educational facilities and/or centers for the handicapped. This technique would not only provide a community with valuable parental feedback, but would directly involve community persons and agencies in the establishment of such a service, as well as in determining who or what would administer the program.

As one example, CAPS is governed by a volunteer Board of Directors, which includes the following officerships: President, Vice-President, Treasurer and Secretary. The remaining members of the Board (eight at the present time) assist in contributing valuable ideas and alternatives in the areas of policy-making, administrative decisions, recruitment techniques, public relations, fund-raising, etc.

CAPS' Board of Directors meet once every two months at the Northern Virginia Training Center for the Mentally Retarded, which is a State regional, residential facility in Fairfax, Virginia.

Representation on CAPS' Board of Directors includes individuals from the fields of nursing, social service work, physical therapy, psychology, special education, law, as well as parents of handicapped individuals. If such persons are not available in your immediate community, consultants from nearby universities and hospitals might be willing to volunteer their time as members of your Board.

If a respite care program will be established under an existing organization or agency, a new Board of Directors may not be necessary to the working of the program.

If a Board is to be created, it is recommended that they develop articles of incorporation and by-laws, in order to qualify for a non-profit, tax exempt corporation status from the Internal Revenue Service under the IRS Code 501(c)(3). This status allows for contributions to an organization which would otherwise be prohibited within the framework of certain private and public service agencies. Such status also entitles an organization to qualify for financial

assistance from local, state or federal funding programs. In some instances, an educational facility, service organization or regional center for the handicapped will already have such status from the Internal Revenue Service.

It is also suggested that corporation insurance be obtained in order to ensure legal and financial protection for the corporation against any possible law suits.

STAFFING A RESPITE CARE PROGRAM

There are various ways of staffing a respite care program. One is the utilization of a staff person under an existing agency to act as the respite care coordinator. If that is not feasible, an individual could be hired expressly for that purpose. If a small group of parents and/or volunteer community persons are initiating the program, the functions of the position might be divided between them, especially if funding is limited at first. Another method of staffing is the establishment of a Board of Directors and/or a paid, respite care coordinator to actually receive and refer requests for respite care from families of handicapped individuals.

CAPS was initiated in 1969 as a community improvement project of a local women's club with a budget of around $500. There were, at that time, no paid staff and modest operating expenses. Eventually a Registrar was hired for a minimal sum to receive and refer requests for respite care. During those early years, the Board of Directors performed the primary functions of recruiting providers of service, informing families of the program, public relations, budget preparation, and so forth.

In 1974, under the direction of a new Board of Directors, a one-time grant from a local service club allowed for the hiring of an Executive Director to assume the day-to-day responsibilities of the service. As time went by, for various reasons, CAPS decided to combine the positions of Executive Director and Registrar into one, paid part-time staff position.

The Director/Registrar of CAPS is a paid, part-time (20 hour week) staff position involving the following functions: 1) maintaining a business telephone in a private home; 2) receiving requests for respite care; 3) recruiting providers of service (called registry members under CAPS' procedure); 4) referring requests for respite care; 5) informing families of mentally retarded and/or physically handicapped persons of the service; 6) assisting in the preparation of budget submissions; 7) performing public relations work; 8) answering any necessary correspondence, and 9) performing any other duties as assigned by the President and/or Board of Directors of CAPS.

The Director/Registrar submits to the President a monthly list of all her major activities, plus a log which includes a numerical record of the total amount of requests for respite care, the number completed, not completed or cancelled, the total number of providers of service used,

how many new families were registered with the program, and the total number of respite care hours provided that month.

In addition, the Director/Registrar submits along with the above papers a copy of the respite care log which lists the name of the handicapped individual, the date(s) of respite care requested, reason for respite, name of registry member providing care, and any comments or problems with the request or actual childcare. Most of this information is obtained from a daily log maintained by the Director/Registrar.

The purpose for these submissions is twofold: 1) to provide the President and Board of Directors with a monthly summary of staff activities and respite requests, and 2) to facilitate an annual summary of statistics and breakdown of usage by families.

To allow for emergency contact, CAPS maintains a 24-hour answering device, attached to the business telephone, which records all incoming phone calls automatically. The Director/Registrar can then play back the recording machine at selected intervals during the day and on weekends in order to respond to any necessary calls. This answering device allows for control of the business phone, since it is in a private home.

CAPS' office hours are from 9:00 a.m. to 1:00 p.m., Monday through Friday, after which all calls are automatically recorded. When the Director/Registrar is on vacation or out of the office for an extended period of time, a taped message on the recorder refers all calls to the President.

It is extemely important that the individual holding the position of Director/Registrar or respite care coordinator be able to communicate efficiently and effectively on the telephone, as well as be receptive to the needs of the families and their children. In many ways, this individual <u>is</u> your program, especially since the receiving of requests and subsequent referring is done principally on the phone. Sensitivity and intuition in determining the qualities and characteristics of providers of service can be a valuable asset in your respite care coordinator position.

SETTING FEES FOR RESPITE CARE

Determination of fees for a respite care program in your community might depend on the composition of your population, the economic level of the families of handicapped persons, whether state or federal funding is available to subsidize all respite care fees, and other such variables.

In 1974 the Board of Directors of CAPS established a fee schedule for respite care that would, ideally, not impose a financial hardship on families of mentally retarded and/or physically handicapped children and adults, but would also adequately reimburse the providers of service (registry members) for their service. The fees for respite care are as follows: $1.50 per hour for the first 2 hours, $1.00 each additional hour; $15.00 for overnight, 24-hour care; $90.00 for 7 days, 24-hour care. These fees might be too high for some areas and should be tailored accordingly.

In most instances, the registry member is paid directly by the family for respite care at the completion of the care. In the event that a family is unable to pay all or part of the fee, CAPS maintains a separate account for subsidized care.

When a family requests respite and financial assistance is justified and available, the Director/Registrar informs the registry member that they will be paid in part or in whole by CAPS, instead of by the family. The subsidy includes the fee for respite care, plus any additional travel expenses incurred when the registry member is providing care in the home of the family. CAPS does not require a financial statement from the family to be eligible for subsidized care, nor use a sliding scale to determine individual fees. This procedure, however, may be necessary in some parts of the country.

Where respite care will include other siblings, normal or handicapped, CAPS requests that advance notice be given to the Director/Registrar and the registry member by the family. In these instances, CAPS suggests an adjustment be made (e.g., 50¢ per hour per child or $5.00 per 24-hours per child) in addition to the established fee schedule.

The only charge for CAPS' referral service is a one-time registration fee of $10.00 requested from the family at the time of registering the handicapped individual. This fee helps to offset the cost of postage and, CAPS feels, is viewed as a small sense of commitment by the family. If a family is unable to pay the registration fee, it is waived.

FUNDING A RESPITE CARE PROGRAM

Each community will have various mechanisms for securing funds to initiate a respite care program. Some will be financed through state and/or local agencies and boards which deliver services to the handicapped; others will be funded by private or public service organizations, local contributions, etc.

Approximately 50% of CAPS' funding comes from state and local matching monies under the Mental Health and Mental Retardation Services Boards of local jurisdictions in the Northern Virginia area. In addition, CAPS has had the continued support of the local Association for Retarded Citizens, which has contributed to CAPS' program each year through United Way funding.

Since these funds are not sufficient to cover all the operating costs, fund-raising through private and public service clubs and organizations is a major activity each year. Sources of funding in your community might include civic and social organizations, service clubs, your local Association for Retarded Citizens, United Cerebral Palsy Association, Society for Autistic Children, Association for Children with Learning Disabilities, the Epilepsy Foundation, and so forth.

Another possible source of funding for the program might be your State Developmental Disabilities Council, under the Federal Developmental Disabilities Office of the Department of Health, Education and Welfare. Each State Council maintains funds for programs serving the developmentally disabled, which includes the mentally retarded, cerebral palsy, epilepsy and autism population.

Other fund-raising activities might include bake or plant sales, church-sponsored endeavors, contributions from private individuals, corporations or foundations, etc.

OPERATING COSTS OF A RESPITE CARE PROGRAM

Operating expenses may vary greatly depending on whether the program is run solely by volunteers, or partly by paid staff; whether the program is run from a private home or in a facility, or whether equipment is already available or has to be newly purchased.

CAPS' method of operation has kept costs down significantly. In Fiscal Year 1976, CAPS' total operating budget was $8,777; in Fiscal Year 1977 (beginning July 1, 1976), a budget of $9,022 is projected. This figure includes the salary for the Director/Registrar, subsidized care, professional consultants (e.g., an auditor), travel reimbursements for staff and/or the Board of Directors, printing (e.g., stationery, fact sheets, brochures, flyers, xeroxing), telephone, postage, corporation insurance, treasurer bond, educational supplies, and the like.

The fact that the Director/Registrar works from her own home and, consequently, eliminates the need for a facility, reduces the operational costs of the program to a great extent. If this procedure is not feasible in your community, you might approach an already existing agency, school or regional center for the handicapped regarding the establishment of a respite care coordinator. This approach would utilize an existing facility as an "umbrella" organization.

It might be that funds for operating costs are sorely limited at the start of the program. Perhaps you could find a volunteer group of parents of handicapped children to initiate the program, using their private home telephone. Access to a xerox or mimeograph machine would allow for forms to be duplicated. Postage might be your initial cost, but the registration fee from the families could help offset that expense. A local church might be willing to provide office space, if a private home is not available or appropriate to the working of the program.

As more funds are obtained, additional supplies and equipment (e.g., a typewriter, adding machine, mimeograph or ditto machine, telephone answering device, etc.) could be purchased. The point to remember is how little it takes to run such a program if a relatively small group of individuals are committed to the concept of respite care as a viable service to families of handicapped individuals in their community.

RECRUITING PROVIDERS OF SERVICE

Recruiting qualified and responsible providers of service is crucial to the effectiveness of your program. How many providers of service you will need to adequately fulfill community demands for respite care is difficult to gauge at first. Some variables might include your handicapped population, whether other respite care programs already exist in private or public residential facilities, the density of your community, etc.

From CAPS' experience, one of the primary sources for recruiting registry members has been the use of free, public service announcement time (generally 10-30 seconds in length) on local television and radio stations. A certain amount of inquiries to your announcement may end abruptly when the details of the program are explained by the respite care coordinator. Some respondents to the media announcement might express hesitancy in caring for handicapped persons, especially if their exposure to the handicapped has been minimal or non-existent.

Informative articles submitted to local and metropolitan newspapers frequently results in many inquiries from potential providers of service. In addition, inexpensive brochures and flyers might be distributed and put up in local libraries, universities and colleges, shopping centers, educational facilities, etc.

Recruitment attempts aimed at nursing students, experienced persons working at day or residential centers for the handicapped, senior citizen clubs, church groups, teacher organizations, and so forth often bring good recruitment results.

CAPS' registry members range in age from 18 years and up. Both men and women serve as providers of service and come from varied backgrounds, including special education, therapy, social service work, psychology, nursing, and teaching. Some are parents of handicapped children and adults, housewives, college students, retired persons, business employees, and generally represent a cross-section of the community at-large.

After an inquiry is made to the Director/Registrar concerning their interest in providing respite care, an application is sent out to them, requesting basic information on the applicant. This information includes their educational background, work experience, availability for providing care, name of homeowner's or tenantowner's insurance, plus the names and addresses of three references, who are sent a

covering letter and attached evaluation questionnaire concerning the applicant.

A personal interview with the applicant and Director/Registrar or President of CAPS is arranged, either in their own home (if that is where the care will take place) or in the home of the interviewer. If the care will be provided in the registry member's home, the interviewer notes any possible safety hazards, such a long flight of stairs, an unfenced yard, a nearby creek, etc.

It is important that persons establishing a respite care program check out local and state licensing requirements concerning childcare, both in and out of the natural home. Some respite care programs maintain providers of service who only go into the home of the child and usually do not have to be licensed. In other programs, private homes have to be licensed for temporary foster or respite care placement of the child or adult.

As a further screening procedure, CAPS requests that the applicant have a recent tuberculosis test and submit a signed medical statement by a physician to the effect that the applicant is free from communicable diseases. The registry member also signs an agreement form between CAPS and themselves releasing CAPS from any liability while the registry member is providing respite care for families.

Once all of this is completed, data on the registry member is recorded on a 5x7 file care, listing any essential information such as their name, address, telephone, marital status and children (if any), availability for providing respite care, where care is preferred, etc. On the back of the registry member's card, the name(s) of all children for whom they have provided respite care, the dates and any problems or comments are recorded.

Sometimes even the best respite care programs fails to meet two specific needs: 1) on-going, daily respite care for working or single parents of handicapped individuals, and 2) occasional long-term respite for pre-foster or pre-residential placement, extended vacations or emergency needs. Thus, it is desirable that providers of service have some flexibility and availability concerning their time schedules. Meeting needs for hourly, overnight and weekend care is generally less of a problem and, fortunately, is usually the prevailing need.

TRAINING PROVIDERS OF SERVICE

The training facet of a respite care program is vital to the quality of provision of care for the handicapped. The degree of training can, in some instances, depend upon the types of individuals who demonstrate an interest in providing care. In addition, the frequency of training providers of service will depend upon the number of persons who respond to your recruitment efforts, as well as a community's ability to coordinate training consultants and sessions.

All three of CAPS' professional training consultants are members of the Board of Directors and volunteer their time. If professional or paraprofessional training consultants are not readily available in your community, it is suggested that you approach professional lecturers or educators at nearby universities, medical colleges or agencies serving the handicapped to assist you in the training.

On the average, CAPS holds its training sessions four times a year at the Northern Virginia Training Center for the Mentally Retarded, which is a State regional, residential center in Fairfax, Virginia. Training is divided into two parts: 1) a six-hour weekend session, and 2) a three-hour weekday evening session. In both sessions, mentally and physically handicapped residents are brought into the sessions to help demonstrate certain techniques and conditions, as well as allow the providers of service an opportunity to feed, fluid, and hold a handicapped child.

The first training session begins with an overview of handicapping conditions, including developmental disabilities. This is presented by either the president of CAPS or a Board member who is a director of a special education center. Emphasis is placed on the fact that the retarded and handicapped are not unlike "normal" individuals in their needs and feelings. With the aid of a multi-handicapped resident, a registered nurse discusses first aid, particularly in cases of emergencies. Emphasis is placed on seizure activity and control, especially in the case of cerebral palsy children and adults. Discussion and demonstration follows on the administration of medications, feeding, giving fluids, play activities, etc. Special emphasis is placed on the need for providers of service to have poison control phone numbers at their ready disposal and instruction on how to handle such a situation. After a short break, a psychologist discusses emotional disturbances, hyperactivity and the most effective techniques for handling the "acting-out" child or adult. He then shows a videotape film which demonstrates parental application of behavior modification for children with inappropriate behaviors. Discussion might also include how to handle eating, bedtime, and discipline problems, parent

separation, overprotectiveness of the individual, etc. Following lunch, the registry members visit two residential units at the Center and are encouraged to interact with the residents as much as desired. This first session ends with an open discussion of the day's presentations.

The second training session begins with a short presentation by a registered nurse specializing in geriatric care, including stroke victims. Specific needs and fears peculiar to the elderly disabled should be discussed and recognized as a growing community need in this country. Using two or three handicapped residents, a registered physical therapist demonstrates proper lifting, holding, positioning and handling of a handicapped individual. Since cerebral palsy is often a primary or secondary characteristic of a retarded or handicapped person, the therapist discusses the various forms of the condition and how to properly deal with them. She also demonstrates various types of special equipment (e.g., wheelchairs, braces, helmets, etc.) that might be used by a handicapped individual. Lastly, there is a panel composed of both experienced registry members and parents who have used the service. After introductions, the panel responds to questions concerning the family impact of having a handicapped child, reasons parents need respite care, what they expect from a provider, what motivates persons to provide respite care, their feelings toward the handicapped, what providers should expect from the families, etc. An explanation of CAPS' referral procedure completes the training.

Supplemental training resources might include agency-sponsored (e.g., a local Association for Retarded Citizens) films, slides and publications on the handicapped, books on pertinent subjects, and visits to nearby centers for the handicapped. Inexpensive booklets and mimeographed handouts on subjects relevant to care for the handicapped is another complementary training component. Other subjects covered might include role playing and recreational therapy, causation and prevention of developmental disabilities, basic skills in activities of daily living, occupational therapy, the impact of the handicapped child on other siblings in the family, and so forth.

In some instances, CAPS' applicants who have had training in the handicapped or retarded are exempt from attending CAPS' training sessions and are put on the registry after all the preliminary procedures have been satisfied and completed.

INFORMING FAMILIES OF A RESPITE CARE PROGRAM

Regardless of the composition of the area in which you reside, there are bound to be families in need of short-term relief care for the handicapped members of their family. In order to allow for as many people as possible to be served, CAPS has no age or handicapping restrictions on who is eligible to receive respite care. Consequently, CAPS' client makeup include the mentally retarded, emotionally disturbed, cerebral palsy, physically handicapped with no accompanying retardation, incapacitated elderly, the deaf, blind, etc.

In the beginning, a community program might have to set some restrictions regarding age or handicapping conditions, due to the limitations of providers of service, or other variables.

To effectively inform families of mentally retarded and/or physically handicapped individuals of a respite care program, it is suggested that a community utilize public service announcement time on local television and radio stations (which is free as a community service in most localities). Another way to inform your community is to submit informative, human interest articles to local and metropolitan newspapers.

One direct public relation technique is to ask local educational and vocational facilities to send home with each enrolled child or adult an informative fact sheet or brochure on your service. CAPS also puts up brochures in local libraries, shopping centers, college and university campuses and nursing schools. Your local Association for Retarded Citizens, public and private school systems, public health nurses and social service or welfare departments should be vehicles in informing the community of a respite care program. Good community dialogue between agencies and their directors and staff encourages the referral of clients for respite.

In an effort to encourage communication, CAPS sends out newsletters to all families registered with the service and registry members twice a year, informing them of how the service evolved, any changes in policy or procedure, etc. CAPS also sends families who use the service an evaluation questionnaire after each respite care, inquiring about both our service procedures and the quality of care by the registry member. This mailout also helps keep CAPS' records updated.

Families on CAPS' registry use respite care for emergencies, vacations, routine reprieve (e.g., a night out, shopping, meeting doctors' appointment) and as a primary alternative to institutionalization of the handicapped.

REFERRING REQUESTS FOR RESPITE CARE

After providers of service have been recruited and put on the registry, families have been informed of the service, and a Registrar or coordinator assigned, actual referring of requests for respite care can take place.

CAPS entire referral system is based on using 5x7 cards maintained in a file box by the Director/Registrar. One set of cards consists of the registry members, and the other consists of the families. The cards on registry members are broken down further into whether they can provide care only in their own home, in the home of the family, or both places.

On each registry member's card there is information which includes their name, address, home and/or business telephone, birthdate, data on acceptance by CAPS, educational and work experience, and their availability and preferred place for providing respite care. This information is obtained from the registry member's application form.

The information on the family card includes the child's name, birthdate, date they registered with CAPS, parents or guardian's name, address, home and/or business telephone, emergency contact, physician name and phone, hospital preferred (if necessary), dentist name and telephone, school, short medical history, type of handicap and preferred place for respite. All of this information provides a quick and ready reference when a family phones in to request respite.

When a family who is new to our program telephones and requests service, the Director/Registrar sends them an application form to be filled in and returned to the Director/Registrar. On this form is a request for a one-time $10.00 registration fee. If a family is unable to pay the fee, it is waived. After the application form is returned, information from the form is then typed on the family card and put in the file box. The cards are filed by the last name of the handicapped individual.

At the time of the request, either by pre-registered or newly registered families, the Director/Registrar takes down the pertinent information and goes through the cards on the registry members to refer the best qualified person based on the particular needs of the child, availability of the registry member, and the location preference of both parties. In cases of emergency requests, the family application form is waived for the time being and the request is filled, if possible.

At times the Director/Registrar can complete a request

for care with one phone call to a registry member; other times many calls to different registry members are necessary. Sometimes CAPS is simply unable to complete or fill the request, because of the large volume of requests received that month, the short notice given by the family to the Director/Registrar, and whether preference for place of respite can be satisfied.

Once a registry member is secured, the Director/Registrar phones the family back and gives them relevant information on the registry member. The parent then contacts the registry member and sets up the time and date of respite care, as requested to the Director/Registrar. If care is to be overnight or longer, or if the child or adult has specific needs that require further discussion or demonstration, CAPS recommends that a meeting be arranged between the registry member and family in advance of the respite. After the request is filled, the Director/Registrar records on the back of the both the registry member and family card the dates, hours and names of providers of service, the reason for the request and any problems or comments. This procedure allows for a cross-reference system and provides a ready observation of who, when and where. As each request comes in to the Director/Registrar, it is recorded on a chronological log maintained by the Director/Registrar.

CAPS' procedures involve various forms that are filled out by the parent prior to and at the time of respite. These forms include: 1) a CAPS' liability release form signed by the parent(s); 2) a signed, notarized release form which allows the registry member to secure any necessary medical attention that the handicapped individual may require, and 3) a three-page medical and emotional summary on the handicapped person. CAPS also requests that the parents write down, in detail, all medication instructions for their child or adult. If a provider of service plans on taking the person in their own car, either to satisfy their own needs or as an "outing" for the handicapped, it is recommended that the parent sign a release form in advance.

When the respite care has been completed, CAPS sends out questionnaires to both the registry member and family, asking them for their comments on the respite itself, as well as on CAPS' procedures. These questionnaires are retained in the individual file folder on registry members.

In the event that the respite care is cancelled, either by the registry member or the parent, the Director/Registrar is notified and informs all necessary persons.

Three situations occur occasionally within the referral and completion system and should be mentioned. First, approximately 16% of all respite care requests to CAPS involves the caring of "normal" siblings, as well as the handicapped child, especially when care is being provided in the home of the family. CAPS has found that this situation is best resolved between the individual registry member and the family at the time the request is referred. CAPS does, however, insist upon knowing in advance if other children or adults will be staying in the family home, so that the registry member is informed. If the provider of service agrees to care for any additional members of the family, there is a slight adjustment in the fee, as mentioned previously under that subject matter.

Secondly, it occasionally happens that a family exhibits some reluctance in filling out the forms involving liability and medical matters. It should be emphasized to the parents that these forms are designed to provide the registry member with all the information necessary for responsible emergency and/or routine care. All releases should be left with the registry member by the parent at the time of the respite or, if convenient, prior to the actual care. It also helps if the providers of service have an extra set of forms kept at their homes in case of emergency respite needs.

Thirdly, in the event that a registry member is suddenly taken ill or is unable to complete the respite care, a substitute registry member is secured by the Director/ Registrar. To allow for this situation, CAPS requests prior written permission from the family, which is part of the liability release form.

In some instances, a request for respite or another form of service will have to be referred to other local agencies (e.g., a regional residential center, social service or welfare department, mental health facility, etc.). For this reason, it is essential that individuals involved with the respite care program familiarize themselves with available service agencies and programs in their community.

OTHER RESPITE CARE PROGRAMS

CAPS, as mentioned earlier, is one model of a community-based respite care program. Other state and local agencies have developed different models providing respite care services. These various models fall, generally, into the following categories:

A. Private respite parent homes (or foster parent respite homes) whereby providers of service are screened, interviewed, training and licensed (if required) to provide temporary care for children and adults in their own home.

B. Sitter or homemaker service, whereby a provider of service goes into the home of the family to offer respite care on a short-term basis.

C. Respite group homes, whereby a private home is available, on a 24-hour basis, for respite care for a limited number (usually 4-7) clients for respite. House-parents or house counselors, with supplemental relief help, oversee the day-to-day activities and supervision of the clients.

D. Respite beds within an existing state or private residential facility, whereby a specified number of beds, usually based on availability, are designated for respite care purposes.

The following list of respite care programs and the types of services available, as described above, is provided for your information.

Program	Type of Service (A,B,C,D)
Respite Home Coordinator Hartford Regional Center 71 Mountain Road Newington, Connecticut 06111	A
RISCA Program Director Johnson County Mental Retardation Center 5900 Flint Street Shawnee, Kansas 66203	A,B
New Haven Regional Center 455 Wintergreen Avenue New Haven, Connecticut 06515	A,D

Program	Type of Service (A,B,C,D)
Stepping Stones Center for the Handicapped 5650 Given Road Cincinnati, Ohio 45243	B
Respite Care Program Council for Retarded Citizens 777 Neil Avenue, Suite B-10 Columbus, Ohio 43215	B,C,D
The Big "R" Respite Home P.O. Box 55 San Rafael, California 94903	C
St. Christopher's Hospital for Children Handicapped Children's Unit 2603 N. 5th Street Philadelphia, Pennsylvania 19133	C
State Regional Retardation Center Fergus Falls State Hospital P.O. Box 157 Fergus Falls, Minnesota 56537	D

The above list is not inclusive, but representative of some of the respite care programs presently existing throughout the country.

SAMPLE OPERATING BUDGET

The following line-item budget of the Childcare Assistance Program for Special Children, Inc. (CAPS) for Fiscal Year 1977 (July 1, 1976 - June 30, 1977) is provided for your information as a sample operating budget and to demonstrate the modest amount of funds necessary to the workings of a community-based respite care program.

Personnel Services

Director/Registrar (20-hours a week) (includes CAPS' share of F.I.C.A.)	$5,660

Operating Expenses

General repair of equipment	150
Professional services (auditor, consultant)	200
Travel, routine, @ 14¢ a mile	160
Travel, conference & convention, @ 14¢ a mile	75
Postage and stamps	360
Telephone (business phone in private home)	262
Printing (brochures, xeroxing)	150
Office supplies	275
Educational supplies (pamphlets, books)	50
Office equipment	110
Educational equipment	75
Insurance (Corporation), Treasurer Bond	120
Dues, memberships, subscriptions	50
Subsidized care (for families needing respite)	1,325
Total Operating Budget	$9,022

5 x 7 REGISTRATION CARDS

REGISTRY MEMBER * CAPS' REGISTRY Reg. Date:

Name: Phone: (Home)
(Bus.)

Address:

Birthdate:

Background:

Availability preference:

Will provide care: ____in home of child ____in own home
____no preference

(Front of Card)

CHILDCARE REFERRALS

Dates	Hours/Days	For Whom	Problems/Comments

(Back of Card)

5 x 7 REGISTRATION CARDS

CHILD * CAPS' REGISTRY — Reg. Date:

Name: — Birthdate:

Parents (name, address): — Phone: (Home) (Bus.)

Emergency contact: — Phone:

Doctor: — Phone:

Preferred Hospital: — Phone:

Dentist: — Phone:

School (if any): — Phone:

Type of handicap:

Medical history, special problems:

Childcare desired: ____in home of child ____in home of registry member ____no preference

(Front of Card)

CHILDCARE RECORD

Dates	Hours/Days	By Whom	Problems/Comments

(Back of Card)

CHILDCARE ASSISTANCE PROGRAM FOR
SPECIAL CHILDREN, INC. (CAPS)

APPLICATION FORM FOR REGISTRY MEMBERS

Mr.
Mrs.
Miss_____
Last First Middle (Spouse)

Address:_____
Street City State Zip

Home Phone:_____Birthdate:_____Children's Ages:_____

Employed by:_____

Position:_____Business Phone:_____

Briefly state background interest and/or experience in working with handicapped individuals:_____

_____

_____

Availability for providing care: ____day hourly ____evening hourly
____overnight weekends ____overnight weekdays

Will care for children: ____in own home ____in home of child
____no preference

Education (high school, college, university, other):

Dates Attended	Name of School	Degree	Major

Employment (for last three years):

Dates Employed	Name & Address of Employer	Position

References (list three, other than relatives):

1._____
Name Street City State Zip

2._____

3._____

How did you learn about CAPS' program?_____

_____

Date of this application:_____

Signature:_____

COMPLETE AND RETURN TO:

CHILDCARE ASSISTANCE PROGRAM FOR
SPECIAL CHILDREN, INC. (CAPS)
POST OFFICE BOX 1217
SPRINGFIELD, VIRGINIA 22151

Dear

The Childcare Assistance Program for Special Children, Inc. (CAPS) is a private, non-profit referral program for respite (short-term relief) care for families of mentally retarded and/or physically handicapped children and adults in the Northern Virginia area. This care is provided by individuals (registry members) in their own homes or in the homes of the families. It is essential, therefore, that CAPS' registry members be responsible individuals of high standards who are emotionally mature to cope with the needs of these families and their handicapped children and adults.

Your name was given as a reference by one of our applicants. We would appreciate your filling out the enclosed questionnaire to the best of your knowledge and returning it to the address above at your earliest convenience. This information will be kept confidential.

Thank you for your cooperation.

Yours truly,

(Mrs.) Deanna Shoob
President, CAPS

Enclosure

CHILDCARE ASSISTANCE PROGRAM FOR
SPECIAL CHILDREN, INC. (CAPS)
POST OFFICE BOX 1217
SPRINGFIELD, VIRGINIA 22151

APPLICANT'S NAME:_____

1. How long have you known the applicant? In what capacity?

2. Do you have any reason to question the applicant's moral standards? If so, explain.

3. In your opinion, is the applicant an emotionally stable person? Please comment.

4. Do you feel the applicant is reliable and dependable? If not, explain.

5. Do you have any knowledge of the applicant's ability to work with handicapped children/adults? If so, explain.

6. Is there any reason you feel the applicant is not suited to care for handicapped individuals in her/his own home, or in the home of the individual? If so, explain.

7. Any other comments you wish to make about the applicant?

_____
Reference's name (please print)

_____
Signature of reference

_____
Address

_____

Date_____

AGREEMENT BETWEEN THE CHILDCARE ASSISTANCE PROGRAM FOR SPECIAL CHILDREN, INC. (CAPS) AND THE REGISTRY MEMBER

I, the undersigned registry member, agree that I will abide by the purposes and policies of CAPS.

1. The registry member shall be responsible for the care of any child/adult referred by the Director/Registrar of CAPS, and shall save CAPS harmless concerning any incident of any adverse nature regarding care of the child/adult.

2. The registry member shall participate in CAPS' training sessions or be otherwise qualified as determined by the Director/Registrar.

3. An annual TB test is required, as well as a statement from a physician that the registry member is free from communicable diseases. These forms shall be submitted to the Director/Registrar.

4. All licensing requirements, state and/or local, shall be fulfilled as promptly as possible.

5. The suggested fees for respite (short-term relief) care established by the Board of Directors of CAPS are as follows: $1.50 per hour for the first two (2) hours, $1.00 each additional hour (not to exceed $15.00); $15.00 for 24-hour, overnight care; $90.00 for 7 days, 24-hour care. Fees for respite care shall be paid directly to the registry member by the parent/guardian. In those instances when a family will be receiving subsidized care, CAPS shall pay all or part of the fee to the registry member. In the case of long-term care, financial arrangements may be agreed upon between the registry member and the family.

6. The registry member is responsible for having the parent/guardian sign any necessary forms and for mailing these forms back to the Director/Registrar upon completion of the respite care.

7. Any change in the registry member's living arrangements or status of health which might affect the health or welfare of the handicapped individual will be promptly reported to the Director/Registrar.

8. In the event that the registry member is unable to continue to care for an individual, the Director/Registrar will be notified as soon as possible, so that the agency might have adequate time to make satisfactory arrangements for the handicapped individual's care.

AGREEMENT (continued)

9. Any problems arising during the respite care or between the registry member and the parent/guardian shall be promptly reported to the Director/Registrar.

10. All information concerning the child/adult and his/her family shall be treated as confidential.

11. The registry member shall maintain sufficient liability insurance to cover any accidents that the handicapped child/adult might suffer while on the premises of the registry member's home. In the event such insurance is not in effect, the parent/guardian shall be duly informed.

_____
Name of Registry Member (print)

_____
Signature of Registry Member

_____
Signature of Spouse

_____
Signature of Director/Registrar

_____
Date

CHILDCARE ASSISTANCE PROGRAM FOR
SPECIAL CHILDREN, INC. (CAPS)

REGISTRATION FORM FOR FAMILIES

Name of Child: _____
Last First Nickname

Name of Parent(s): _____
Last First

Address: _____
Street City State Zip

Home Phone: _____ Business Phone: _____

Homeowner's/Tenant Liability Insurance: _____

Child's Birthdate: _____ Referred By: _____

Emergency Contact: _____
Name Relationship

_____
Address Phone

Name, ages of other children at home: _____

Doctor: _____ Phone: _____

Hospital preferred: _____ Phone: _____

Dentist: _____ Phone: _____

School (if any): _____ Phone: _____

Type of Handicap: _____

_____

Brief description of condition, special problems, etc. _____

_____

_____

_____

_____

Immunizations (give exact dates):

Polio _____ Rubella (German Measles) _____
Smallpox _____ TB Tine Test _____
DPT _____ Mumps, other _____

Does he/she have any known allergies? _____yes _____no

If yes, describe: _____

_____

REGISTRATION FORM (continued)

Does he/she have a history of seizures?_____yes_____no
If yes, describe in detail (frequency, length of seizure, etc.)

_____

_____

_____

Does he/she take medication for seizures?_____
If so, what, when and how often?_____

_____

_____

List any other medications taken regularly by child/adult (name, exact dosage, times taken, etc.)_____

_____

_____

Do you prefer childcare:_____in home of the child
_____in home of registry member
_____no preference

CAPS requests a one-time registration fee of $10.00, if financially possible. Please make check payable to CAPS and return the fee with this registration form to:

(Families unable to pay part or all of the fee for respite care are eligible for financial assistance from CAPS, if justified and funds are available.)

_____ _____
Date Signature of Parent/Guardian

AGREEMENT BETWEEN THE CHILDCARE ASSISTANCE PROGRAM FOR SPECIAL CHILDREN, INC. (CAPS) AND THE PARENT/GUARDIAN

I(We) agree that the Childcare Assistance Program for Special Children, Inc. (CAPS) will not be held responsible or liable in any way whatsoever as a result of any incident which might be construed to adversely affect the health, safety or welfare of my(our) child _____, while my(our) child is cared for by _____ _____ _____, a CAPS' registry member. I(We) have fully disclosed to the said registry member all pertinent facts about my(our) child's need and problems, and acknowledge full responsibility for failure to do so.

CAPS, Inc. is hereby given permission to refer my(our) child to the home of another CAPS' registry member or refer another CAPS' registry member to my(our) home in the event that said registry member is unable to render the necessary care.

_____
Signature of Parent/Guardian

_____
Signature of Spouse

_____
Date

MEDICAL RELEASE FORM

(notarization is required)

Name of Child: _____
Last First Middle

Name of Parent(s): _____

Address: _____

Telephone: _____(Home) _____(Business)

_____is in full charge of my(our) child during my absence.

I give her/him permission to request or approve any medical attention needed by my(our) child and to administer medications according to my(our) written instructions below.

She/he will not be held responsible or liable in any way for any accident or illness.

Name of Hospitalization Insurance: _____

Policy Number: _____

Doctor(s): _____

Address: _____

Phone: _____

Hospital Preferred: _____

Dentist: _____

Address: _____

Phone: _____

Medication Instructions: _____

_____

_____

Date: _____ Parent(s) Signatures:

_____

_____

State of Virginia, County/City of _____, To-wit:

Subscribed and sworn to before me this _____day of _____, 19____.

_____
Notary Public

My Commission Expires:

MEDICAL/EMOTIONAL INFORMATION SUMMARY

Name of Child:_____
Last First Nickname

Name of Parent(s):_____

Address:_____

Telephone:_____(Home)_____(Business)

Child's Birthdate:_____Height:_____Weight:_____

Type of Handicap:_____

_____

Name of Child's Doctor:_____

Address:_____Phone:_____

Emergency contact:_____

_____
Address Phone

School (if any):_____Phone:_____

Medical Information

a) Does he/she have a history of seizures?_____If so, describe:_____

_____

b) Does he/she take medications for seizures?_____If so, describe (what kind, times taken, dosage, etc.):_____

_____

c) Does he/she take other medications regularly?_____If so, describe:_____

d) Does he/she have any known allergies to:_____drugs_____ foods _____other. Describe:_____

_____

e) What do you give your child in case of:

Cold:_____ Dosage:_____
Cough:_____ Dosage:_____
Temperature:_____ Dosage:_____
Headache/Sore Throat:_____ Dosage:_____
Upset Stomache:_____ Dosage:_____
Diarrhea:_____ Dosage:_____
Constipation:_____ Dosage:_____
Other:_____ Dosage:_____

f) Does the child/adult have menstrual periods?_____If so, describe:_____

INFORMATION SUMMARY (continued)

Eating Habits

a) Is he/she right or left-handed?_____

b) Can he/she feed him/herself?_____

Drink from a glass/cup?_____Other?_____

c) What are his/her favorite foods?_____

_____Least favorite?_____

_____

d) List a typical daily menu for the child/adult:

Breakfast	Lunch	Dinner

e) Snacks?_____

Sleeping Habits

a) Does he/she sleep in bed?_____In crib?_____

Other?_____. Usual bedtime hour?_____

b) Does child take any toy/blanket to bed?_____

c) Does he/she sleep on back, side or stomach?_____

d) Does he/she awake at night?_____If so, what should be done?_____

Toilet Habits

a) Is she/he toilet trained?_____

b) How does he/she indicate need to use bathroom?_____

_____

c) Can she/he use standard toilet fixtures?_____If not, explain:_____

Does he/she use any special equipment (wheelchair, braces, helmet)?

_____

Can he/she:_____sit up alone_____stand_____walk_____run

_____climb stairs? Other:_____

INFORMATION SUMMARY (continued)

Does he/she have speech?_____If not, describe how he/she makes her/his wants understood?_____
_____Does he/she understand language?_____

Emotional Characteristics

a) Does he/she like to be cuddled and/or hugged?_____

b) Has he/she ever been away from home?_____Ever been cared for by someone other than family?_____

c) If he/she is hyperactive and/or has any emotional problems, describe any behaviors that registry member should know about and what should be done about the behaviors:_____
_____
_____

d) How much supervision does he/she require?_____

Describe a typical day's schedule for the child/adult:
_____
_____
_____

Favorite activities?_____Favorite toys/games?_____Favorite TV programs?_____Other?_____

I can be reached at the following addresses and phone numbers (please list by dates and times of day):

_____ _____
_____ _____
_____ _____

I will return (date and time):_____

Date:_____

Parent(s) Signatures:

_____

_____

CHILDCARE ASSISTANCE PROGRAM FOR
SPECIAL CHILDREN, INC. (CAPS)
POST OFFICE BOX 1217
SPRINGFIELD, VIRGINIA 22151

Dear

The Childcare Assistance Program for Special Children, Inc. (CAPS) is consistently trying to improve its program to provide qualified respite (temporary relief) care to families of mentally retarded and/or physically handicapped children and adults. Therefore, we would appreciate your cooperation in answering the following questionnaire as honestly as possible and returning it to the above address <u>after you have used the service.</u>

1. How and when did you learn about CAPS?

2. Were you satisfied with the care your child/adult received from _____. Please comment.

3. Were you satisfied with CAPS' referral procedure? If not, please explain.

4. What impressed you most about CAPS' registry member and/or service? What impressed you least?

5. Any other comments?

Thank you!

_____
Date

CHILDCARE ASSISTANCE PROGRAM FOR
SPECIAL CHILDREN, INC. (CAPS)
POST OFFICE BOX 1217
SPRINGFIELD, VIRGINIA 22151

Dear

The Childcare Assistance Program for Special Children, Inc. (CAPS) is consistently trying to improve its program to provide qualified respite (temporary relief) care to families of mentally retarded and/or physically handicapped children and adults. Therefore, we would appreciate your cooperation in answering the following questionnaire as honestly as possible and returning it to the above address <u>after you have completed the respite care</u>.

1. Did you receive cooperation from the family of _____ _____in completing required forms and providing you with adequate information to satisfactorily handle the respite care? Please explain.

2. Did you experience any unforeseen problems handling this referral? If so, please describe.

3. Would you like this child/adult to be referred to you again? If not, please explain.

4. Were you satisfied with CAPS' referral procedure? Please comment.

5. Any other comments about this particular referral and/or CAPS' program in general?

Thank you!

_____
Date